

Clinical Trials: Major Evidence for Progress

Compelling evidence for recent progress in Alzheimer's disease may be the growth in clinical testing of new approaches to treatment, prevention and diagnosis.

Clinical trials are the final proving ground for new treatments under investigation. Each trial represents years of creative scientific thinking, careful observation, laboratory study and data analysis.

The large number of trials now underway demonstrates the vigor

of the field and the strength of the dementia research network.

Here are highlights of two federally funded clinical trials.

The Alzheimer's Disease Neuroimaging Initiative

Results of this five-year study look to determine better ways to identify people at risk for Alzheimer's, assess whether drugs being studied are effective and whether brain imaging can help diagnose Alzheimer's,

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Paul Inboriboon to Hike Mt. Kilimanjaro To Raise Alzheimer's Awareness, Funds

If you're out and about in Chicago any time from now into September, keep an eye out for Paul Inboriboon. When you see him ambling along in a new pair of hiking boots and with a backpack filled with 20-30 pounds of canned corn, urge him to stick to his training schedule and take his vitamins.

Thank him, too, for investing six months of his life and thousands of dollars to represent the Association on the "Ascent for Alzheimer World Team," an international team of 10 hiking Mt. Kilimanjaro in Tanzania, Africa, in September to draw attention to the worldwide impact of Alzheimer's disease and other dementias.

"Already this is one very cool experience," Paul said. "I'm training to hike the largest mountain in Africa—the summit is at 19,340 feet—and I am lucky enough to be an ambassador for 81 Alzheimer's Association chapters across the United States, plus 4.5 million Americans with Alzheimer's and their family members and caregivers."

"Preparing for the ambassador part of this trip is easy and very close to home," he said. "I just look around my office – the national office of the Alzheimer's Association – to be reminded of all of the programs, services and support we offer millions of Americans. Then, I only have to think of

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Join Us in Welcoming Our New Multicultural Outreach Manager and Professional Training Institute Director

This spring, our Chapter family has grown with Constantina Mizis and Daniel Kuhn joining us to lead our work in multicultural outreach and professional education and training throughout our 68-county chapter area. Please join us in welcoming Constantina and Dan.

Constantina Mizis

Constantina Mizis, our manager of multicultural outreach since April, already is hard at work sharing our vision and expanding education and awareness opportunities.

"Our culture plays a major role in how we feel about life, family, health and illness," she said. "Because Alzheimer's disease and other dementias affect us all, it's very important that our information, education and support are presented

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Alzheimer's Association Vision & Mission

Our vision is a world
without Alzheimer's disease.

Our mission is to eliminate Alzheimer's disease and other dementias through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementias through the promotion of brain health.

Clinical Trials

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monitor its progression and identify people at risk for developing it.

The study, supported by a \$1 million contribution from the Association, seeks about 200 participants with no cognitive symptoms, 400 people with mild cognitive impairment and 200 in the early stages of Alzheimer's.

NIA Genetics Study


The Alzheimer's Association and the National Institute on Aging (NIA) are partnering to create the nation's largest repository of genetic material from families affected by late-onset Alzheimer's to speed the discovery of genes involved in Alzheimer's.

The aim is to recruit at least 1,000 families that have at least two siblings that developed Alzheimer's or serious memory loss after age 60 and at least one relative over 50 with memory loss or over 60 with no memory loss.

NIA leads the federal research effort on Alzheimer's and age-related cognitive change. NIA is a component of the National Institutes of Health (NIH) that is part of the U.S. Department of Health and Human Services.

For more information, visit www.alz.org. The NIH also has an online medical research database at www.clinicaltrials.gov listing nearly 100 trials recruiting participants who have Alzheimer's.

Know Your Charity

If you don't see this mark, your donation is not going to the Alzheimer's Association, the world leader in Alzheimer research and support,  and the first and largest voluntary health organization dedicated to finding the cause, treatments, prevention methods and an eventual cure for Alzheimer's disease.



You're cordially invited to join us at one or all of our Memory Walks® this fall to raise awareness and funds for programs and services. We look forward to receiving your RSVP.

Until then ... thanks for forming your team of family, neighbors, friends and colleagues to show the world how many of us know about the long-lasting and far-reaching impact of this disease and how to help us toward a world without Alzheimer's.

Until then ... thanks for walking or supporting our cause in honor or in memory of someone with Alzheimer's - a family member, someone in a friend or co-worker's family or someone in your town.

"Memory Walk® is a commemoration of lives touched and forever changed by the disease," said Lisa Lee, associate director of special events.

"Memory Walk® is also how we all can give a few hours to call attention to its impact in our lives - and a few dollars to help the Greater Illinois Chapter help more than half a million Illinoisans affected by the disease who are in our 68-county area."

"As you invite people to be on your Memory Walk® Team or to support your team financially, remember how close this disease can be to us all:

- ✓ 1 in 3 of us knows someone with Alzheimer's
- ✓ 1 in 10 has a family member with Alzheimer's
- ✓ 1 in 10 is an Alzheimer caregiver
- ✓ People may live with the disease for eight years, on average

Thanks, again, for forming a Memory Walk® Team, for turning pledges of support into donations, and for joining us at Memory Walk®!

Memory Walk® 2006

Saturday, September 16

Joliet – Rock Run Forest Preserve
Rockford – Klehm Arboretum
Springfield – Washington Park

Sunday, September 17

Chicago – Montrose Harbor

Saturday, September 23

Kankakee – Farmers Market, Town Square

Sunday, September 24

McHenry County - Lippold Park, Crystal Lake

Saturday, September 30

Urbana – Meadowbrook Park

Saturday, October 7

Bloomington – Constitution Trail

Memory Walk® is the largest national fundraiser for Alzheimer programs and services with 600+ walks nationwide. Memory Walk® is presented by Genworth Financial. Creative Memories and Kindred Healthcare, Inc. are the official national sponsors. Visit www.alzheimers-illinois.org/memorywalk or call us to register!

Memory Walk® Checklist:

- ✓ RSVP Today
- ✓ Register Your Team
- ✓ Set Your Team Goal
- ✓ Recruit Team Members

You're Invited To Become An Alzheimer Advocate!

Alzheimer Advocates speak up in support of quality care and good quality of life for more than half a million Illinoisans impacted by Alzheimer's today.

Greater Illinois Chapter Alzheimer Advocates also are members of the Illinois Chapter Network, the leading Alzheimer advocate group in the state, and that includes volunteers from all Association chapters serving Illinois counties.

As an Alzheimer Advocate, here's how you can help!

- Advocates help us forward our public policy priorities** to improve quality of life for Illinoisans impacted by Alzheimer's.
- Advocates make calls or write to legislators** on these priority areas.
- Advocates consider being "Lead Advocates"** to cultivate relationships with legislators to heighten awareness of the impact of Alzheimer's in Illinois and the need for quality care for people with dementia.

Our goal is to have a Lead Advocate in every legislative district in our 68-county chapter area by July 1.
- Advocates stay on top of policy and legislative issues** through alerts and updates from the chapter.

To become an Alzheimer Advocate, contact Brian Schwarberg, Public Policy Director at 217.726.5184 or brian.schwarberg@alz.org.

24-Hour Helpline

800.272.3900 (TDD: 866.403.3073)

www.alzheimers-illinois.org

All Alzheimer Advocates Cordially Invited To Public Policy Forum in Washington in June

The Alzheimer's Association's 18th Annual Public Policy Forum is June 3 - 6 in Washington, D.C., with programs and events at the Grand Hyatt Hotel, on Capitol Hill and at the Lincoln Memorial.

Participants will receive a wealth of tools and tips for successful Alzheimer advocacy at federal and local levels, especially during visits to Capitol Hill on June 6 to meet legislative leaders and their staff. For more information, visit <http://www.alz.org/forum>.

Legislative News You Can Use

Illinois Legislation

During the General Assembly's Spring Legislative Session, the Association introduced SB 2173, a bill calling for a tax credit for the purchase of long-term care insurance. Although the bill passed the Illinois Senate by a vote of 56-0, it did not make it out of the House of Representatives Rules Committee. Thanks to all advocates who helped with this legislation; we will work on this bill in the House next year.

U. S. Senate Restores Funding for Alzheimer Research

The U.S. Senate overwhelmingly approved additional funding for health and education programs that were slated for deep cuts in fiscal year 2007. Senators voted 73-27 for an amendment by Sen. Arlen Specter (R-Pa.) and Sen. Tom Harkin (D-Iowa) to add \$7 billion for health, education and labor programs to the president's budget request during debate on budget legislation passed by Congress that sets overall spending limits for federal programs. Passage of this amendment is a "win" in our fight to restore federal funding for Alzheimer research and care programs and is a critical first step in the budget process. The Senate also passed the Budget Resolution bill, setting the stage for action when the House of Representatives begins debating its version of the legislation.

Note: Monitor legislation in the General Assembly at: <http://www.ilga.gov/>.

Association Receives Award for Excellence

The Alzheimer's Association received the American Society of Association Executives' Award for Excellence for disaster response work and leadership during and after hurricanes Katrina and Rita struck the Gulf Coast last year.

The Association's "Help Team" of dozens of volunteers from the National Office and chapters worked two-week shifts at our chapters in Louisiana and Mississippi to help people with dementia (estimated 115,000) and their families there with care consultation; training for emergency responders and residential care facilities; outreach to state agencies and care facilities; and Safe Return® enrollment. The Association also launched a Hurricane Relief campaign for Association staff and volunteers nationwide to raise \$500,000 to support the chapters. The Greater Illinois Chapter pledged \$5,000 to the campaign.

Here's Why we are Working 24-7 to Educate, Improve Care and

If 19th Century poet William Wordsworth wrote today about the “world being too much with us,” we would agree that many aspects of our lives overlap, intersect and run parallel, especially in relation to aging and culture, and that the world is shrinking by virtue of technology. We also would say it's exactly why we are energized to move even faster and to reach out even farther to meet the needs of people affected by Alzheimer's and other

Association's "Effective Treatments Initiative" to Elevate Urgency of Alzheimer's and Speed Development of Safe Alzheimer Treatments

The Association's Effective Treatments Initiative (ETI) aims to elevate the urgency of Alzheimer's and ensure safe treatments are developed, tested and made available to the public as quickly as possible.

“Alzheimer's is a devastating disease and the need for treatments is more urgent than ever with 77 million baby boomers turning 60 this year,” said Stephen McConnell, vice president of advocacy and public policy for the Association.

“Through ETI, we are responding to our constituent's needs as people with Alzheimer's and their families are speaking up and demanding more information about and access to clinical trials and the process of drug development,” he said.

“We also are taking the lead to make the urgency of the disease and its treatments known to the public and federal government officials, who have it in their power to reduce the disability of the disease and save lives.”

The ETI's goals are:

1. Educate the public about the value of clinical studies, including clinical trials, and increase enrollment in such studies .
2. Raise the profile and priority of Alzheimer's at all levels of drug development.
3. Involve people with the disease in drug development and review processes.
4. Increase private and public funding for Alzheimer research.

ETI also will be a platform for continued discussion among scientists and people

with Alzheimer's about the risks and benefits of clinical trials that began during a Research Roundtable convened by the Association in December 2005.

The multi-disciplinary advisory committee guiding ETI includes scientists, people in the early stages of Alzheimer's and their families, experts on FDA approval processes, and others. The Association also seeks input from government agencies and the pharmaceutical industry and is coordinating with organizations having similar or complementary goals.

Everyday Technologies May Help People with Alzheimer's, Families, Caregivers

Can television, computers and video cameras make life better for people affected by Alzheimer's? The Association, Intel Corporation and others in the Everyday Technologies for Alzheimer Care (ETAC) consortium have awarded \$800,000 in four grants to find out.

“ETAC is leading the way to discover ways to use available advanced technologies to save costs associated with providing care, ease caregiver stress and help people live better, safer, more fulfilling lives,” said William Thies, Ph.D., Alzheimer's Association vice president of medical and scientific affairs.

Culture Shapes View of Alzheimer's

Beliefs vary in African-American, Hispanic and Hmong American communities about what causes Alzheimer's disease and ways to prevent and treat it, according to recent studies.

- Many more people in the African-American and Hispanic study groups said stress was a significant factor for Alzheimer's compared with Caucasians.
- In the Hmong American community, religion influences the perceived cause of dementia in older people, with most caregivers viewing elder confusion as a normal part of aging.

Support Research for a World Without Alzheimer's Disease

dementias. It's because we know how close this disease is to so many of us and because we know the impact Alzheimer's and other dementias already has and will continue to have on individuals, families and caregivers, as well as communities, businesses, health systems and our government. Here is a variety of information about aging and dementia that drives our work toward a world without Alzheimer's disease.

Long-Term Care Costs Rising, Many Don't Have Long-Term Care Plans

The average cost of long-term care in U. S. assisted living facilities, nursing homes and in people's homes rose in the past year, according to the "Cost of Care" survey from Genworth Financial.

In addition, 65% of Americans surveyed in a national poll said they had not made long-term care plans for themselves or a spouse.

Here are survey highlights:

- Assisted living and in-home costs rose more sharply than nursing home care.
- The average annual cost rose 7% for a private one-bedroom unit in an assisted living facility and 2% for a private room in a nursing home; home health aide costs for in-home care increased by 13%.
- On average, cost of care in urban areas is 17% higher than in non-urban regions.
- Within 48 states, the annual cost of care in nursing homes was higher than the average income of residents.

National poll highlights include:

- Most people recognized the need to prepare for the cost of long-term care, but were largely unprepared.
- Many felt their savings would be adequate to cover long-term care costs and Medicare would cover long-term health care costs.
- Many wrongly believed they had insurance protection.

More survey and poll information is at Genworth.com.

Baby Boomers Will Change U.S. Aging

Baby boomers are just starting to turn 60 and will redefine what it means to grow older in America, according to a U.S. Census Bureau report, "65+ in the United States: 2005," that was commissioned by the National Institute on Aging (NIA). Among the trends noted:

- ✓ The U.S. population age 65 and over is expected to double within the next 25 years. By 2030, almost one of every five Americans (72 million people) will be 65 or older. The fastest-growing segment includes those 85 and older.
- ✓ Today's older Americans differ from earlier generations—they live longer, have lower rates of disability, achieve higher levels of education and less often live in poverty.
- ✓ While the health of older Americans is improving overall, many are disabled and suffer from chronic conditions. The proportion with a disability fell significantly from 26.2% in 1982 to 19.7% in 1999, but 14 million people age 65 and older reported some level of disability, mostly linked to chronic conditions such as heart disease or arthritis.

"We have made a lot of progress in improving the health and well-being of older Americans, but there is much left to do," says NIA director Richard J. Hodes, M.D.

Other report findings:

- ✓ In 2000, 4.5% of people age 75 to 84 and 18.2% of those 85 and older lived in nursing homes. About three in four older nursing home residents are women.
- ✓ In general, heart disease and cancer continue to be leading causes of death (rates vary by age, gender and race).
- ✓ Approximately 80% of seniors have at least one chronic health condition, and 50% have at least two chronic health conditions, which often lead to disability. Arthritis, heart disease, hypertension, diabetes and respiratory disorders are some of the leading causes.

Paul Inboriboon *Continued from Page 1*

my wife Melissa and her family – to me they represent all the families who have faced the poignant and lasting impact of this disease. I am hiking in honor and memory of Minnie, my wife’s grandmother, who had Alzheimer’s and died in 1998, as well as all the others who have faced and will face this disease.”

Paul is just as driven to complete his six-month training regimen for the hike. He is doing cardiovascular workouts and hiking training three times a week for peak stamina, endurance, and strength, and taking a series of shots for diseases like yellow fever and malaria. He also is packing his kit, including a sleeping bag that will provide insulation to -20 Fahrenheit, good hiking boots and a camera.

“While this trip is going to be as visually spectacular as a hike in the Grand Canyon, there won’t be hand rails, rest areas and a hotel to go back to at the end of the day,” Paul said with a grin. “We will carry our own gear, sleep in tents and just have to get used to not being able to use laptops and cell phones.”

Paul believes a key to a successful hike will be everyone having good senses of humor and interesting stories to tell.

“I’m looking forward to meeting the team, including Jean from the Greater Michigan Chapter, plus hikers that I hear are coming from the Netherlands, Canada, the Dominican Republic and Hong Kong,” he said. “We’ll be together for almost two weeks and this will be a golden opportunity to learn how things are in other countries and talk about how each of our countries meets people’s needs.”

“I see this hike as a very positive way to raise awareness of the lengths – and heights – we’re reaching to put an end to this disease,” Paul said. “I really hope people hear

about what we’re doing and take time to learn more about Alzheimer’s and what they can do to help the 4.5 million Americans and also the 18 million people worldwide who have Alzheimer’s disease or another dementia.”

The Alzheimer’s Association – Greater Illinois Chapter supports Paul’s efforts and welcomes public support. Monies raised will be used to provide information, support and programs for the more than half a million Illinoisans affected by Alzheimer’s who are in the chapter’s area.

For information or to make a donation visit, www.alz.org/theclimb.

Dinner Table Trivia: The Hike and Mt. Kilimanjaro

- The hike should take 6 days and 7 nights.
- Hikers plan to reach the summit on September 21 (World Alzheimer’s Day).
- 40 African guides/porters plus two Canadian guides (one a doctor) are hiking, too.
- Alzheimer’s Disease International, based in London, and the Alzheimer Society of British Columbia are coordinating the event. The Alzheimer’s Association is a founding member of ADI.
- This year, hikers commemorate the 100th anniversary of Dr. Alois Alzheimer describing the disease in 1906.
- Mt. Kilimanjaro is the largest mountain on the African continent.
- Its summit is at 19,340 feet (more than 15,000 feet above sea level and higher than a stack of 13 Sears Towers).
- The mountain is made up of three extinct volcanic cones - Kibo, Mawenzi and Shira. The rim of Kibo’s summit crater (1.5 miles wide) has the highest mountain peak in Africa. Mawenzi is one of the largest volcanoes in the world.

Ways to Support the Alzheimer’s Association - Donate Life Insurance

The need for life insurance likely will decline as people age, increasing its popularity as a charitable gift. Because gifts of life insurance are usually gifts of ordinary income, they are deductible up to 50 percent of your adjusted gross income. If necessary, you may carry over the deduction for an additional five years.

Options for donating life insurance to the Association are:

1. Gift of an Existing Policy. This is an outright gift you make. The Association will take either the paid-up policy’s cash value or retain the policy for its face value after your lifetime.
2. Create a New Policy. You take out a new policy and name the Alzheimer’s Association as owner and beneficiary. Premium payments, usually gifted to the Association, are income tax-deductible. Using this method, the annual premium is about one to four percent of the initial face amount of the policy.
3. Use the Beneficiary Clause as a Revocable Gift. You will retain ownership of the policy as an asset for your financial security and name the Association as a primary or partial beneficiary of the policy.

Mark Your Calendars ...

Public Education Programming

Maintain Your Brain®: How to Live a Brain-Healthy Lifestyle – for everyone interested in brain health. May 25—Danville
• June 22—Rockford

Partnering With Your Doctor – a workshop to develop skills for interacting with health professionals for caregivers and people with memory loss. May 9—Chatham • May 23—Carterville • June 7—DeKalb • June 14—Crete

Conferences for Family Caregivers

May 25 – Springfield - "Synchronizing Science and Support," 11th annual conference for health professionals and caregivers

November 11 – Rosemont - "Alzheimer's Association Family Conference: Support for Families Living with Memory Loss," 4th annual conference for family and friends of people with Alzheimer's and other dementias. *Registration opens September 1.*

About The Newsletter ... You received this newsletter because you indicated an interest in Alzheimer's, dementia or brain health, attended a chapter program or event, contacted us through Helpline or our Web site or made a donation.

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Welcome New Staff *Continued from Page 1*

in ways that appeal to different groups and present information from different perspectives."

Constantina knows all about multicultural environments. Raised in Mexico by her Grecian father and Mexican mother, she came to Chicago in 1993 and was as a Culture Consultant, developing curriculum and Spanish-language materials for Catholic and Montessori schools and Greek-American academies. Since 1998 she worked in the family ministry program for the Archdiocese of Chicago focusing on health, immigration and domestic violence programs in Latino communities through St. Viator's Church. She also was a member and volunteer of the Social and Justice department of the Archdiocese.

Daniel Kuhn

Daniel Kuhn, M.S.W. joined our staff on May 1 as director of the Alzheimer's Association Professional Training Institute through which we offer cutting-edge, interactive education and resources for new and seasoned professionals to gain skills and expertise in Alzheimer care practices. He comes to the chapter with two decades of experience in the fields of Alzheimer's disease and professional education, most recently from Mather Institute on Aging where he was the education director since 1999. He also served as both clinical social worker and director of clinical education at the Rush Alzheimer's Disease Center in Chicago. Dan also worked for the chapter as a social worker from 1987 to 1992. Dan has written several books and training curricula, including "Alzheimer's Early Stages: first steps for family, friends and caregivers" and co-authored "Making Sense of Memory Loss" curriculum with Melanie Chavin, vice president of program services for the chapter.

"Multicultural outreach and professional education and training are two of our topmost priorities," Melanie said. "We look forward to expanding our programming and expanding relationships to educate and support people affected by Alzheimer's, including working with providers, faith-based organizations, Alzheimer Disease Centers, state agencies, health coalitions and councils."

Note to health professionals in all care settings: Visit our Web pages for program listings at www.alzheimers-illinois.org/pti or e-mail aapti@alz.org.

Note about Hispanic/Latino Resources: We offer a variety of resources for non-English speaking audiences, including Spanish-language materials and links to other sites of interest to Spanish-speaking visitors. Visit www.alz.org/hispanic/overview.asp and www.alz.org/hispanic/overviewsp.asp. The site also has a Message Board for Spanish-speaking care professionals and families to ask questions, share experiences and connect with others whose lives have been affected by Alzheimer's and memory loss. Visit www.alz.org/espanollogin.htm.

How to Contact the Greater Illinois Chapter

We're as close as your phone or computer for information, support and access to community resources

24-Hour Helpline 800.272.3900
(TDD: 866.403.3073)
We offer translation in 140
languages and dialects

Chapter Web site www.alzheimers-illinois.org
The link to Helpline e-mail is in the
upper right-hand corner of our home
page.

National Web site www.alz.org

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We are fighting on your behalf 24/7
to give everyone a reason to hope.

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